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## MESSAGE FROM THE CHAPTER CHAIR

Dear SBANENY Friends,

I can't believe it's October already. Fall has begun and winter is right around the corner. The leaves are changing, the weather is changing, and we've had a few changes in the office as well. Two months ago we welcomed a new staff person into the office, Rachael Stohl, who is working part-time as a case manager. Soon we will be saying goodbye to Bobbie Hlat. Bobbie has worked in our office, also part-time, for the last two years. We want to thank Bobbie for all of her hard work and hope she stays in touch. We are also looking to add some new members to our board for the coming year. We are looking for people with experience and expertise in marketing and PR, legal, and accounting. If you are interested or know someone who would be interested in applying, please contact our office for more information.

As you know, October is Spina Bifida Awareness Month. In recognition of this, Schenectady City Council introduced a resolution on September 23<sup>rd</sup>. At some time during the month we are anticipating that the dome of Schenectady City Hall will have one side lit in turquoise to help bring attention to the resolution and spina bifida awareness. Check it out if you get the chance and let us know when you see it!

We have been working hard to explore new ways to reach out to individuals and families. If you have ideas, please share them with us. Your suggestions are always welcome!

This past week we had an event for the adults called "Hints for a Healthier Mind & Body." Thank you to Barbara Devore for putting this together. On December 7<sup>th</sup> we will be having our "Dare to Dream – Look How Far We've Come!" fundraising event featuring The Singing Anchors. If you or your organization would like to become a sponsor for this event, please contact Karen Wentworth at 518-399-9151 as soon as possible.

I hope you are enjoying this beautiful fall. Don't forget to check us out on Facebook!

## SBANENY

### Board of Directors

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**Disclaimer:** *Spina Bifida Association of Northeastern New York does not endorse or recommend products, services or manufacturers and assumes no liability whatsoever for the use or contents of any product or service mentioned herein. The information provided in this newsletter is for informational, educational and entertainment purposes only. It is not intended as medical or professional advice.*

# SBANENY NEWS

## ADULT MEETING OCTOBER 12<sup>TH</sup>

### “HINTS FOR A HEALTHIER MIND AND BODY”

On October 12<sup>th</sup>, the Adult Committee sponsored a conference on “Healthy Living”. The day started with a workshop addressing “Using Mindfulness to Reduce Stress and Increase Personal Well-being”. During the workshop we identified what stresses us out individually, and where/how we feel the stress. We ended with an exercise to help calm us when we feel stressed.



The next session gave us tricks to eat healthy on a budget. We created a few delicious snacks (pizza and smoothies) which we consumed as part of our lunch.



After lunch, we finished up with chair Zumba, where we moved, danced, and laughed a lot!

Our next Adult event will be a meeting on developing healthy relationships, scheduled for January. The Committee has also begun planning a game/movie night for the middle of winter, as well as presentations on urology challenges and how to access benefits. Our next planning meeting is scheduled for November. If you are interested in participating in our planning group, please call the office. The committee is always looking for new members and ideas!



## SBANENY LENDING LIBRARY MATERIALS

The SBANENY lending library has a variety of books and resource materials that are available for loan. Topics include health, education, parenting a child with special needs, accessibility, and much more. We have books for children that help to address topics of concern that they might have.

If you are looking for print resources about particular topics, contact our office. Books are borrowed and returned through the mail, or are available at some SBANENY programs.

Please remember to return your lending library resources as soon as you are done with them so that they are available for other individuals and families.



## FRANK BUCINO MEMORIAL SCHOLARSHIP

Recently we met with Diane and Frank Bucino, to assist with their plans to establish a scholarship in memory of their son Frank Bucino, Jr. who passed away on July 15<sup>th</sup>.



Frank had an Associate of Arts Degree from County College of Moris. He was a junior attending Binghamton University's Harpur College.

Frank's parents are establishing a scholarship in his memory to honor his value of education and his desire to help others who have Spina Bifida. The scholarship will be managed by Spina Bifida Association of NENY. Details about the scholarship, as well as application process, will be announced in the SBANENY January 2014 newsletter.

### **Are you pursuing an educational or training goal?**

Applications for Helen Mertens Educational Scholarship and the Frank Bucino, Jr. Memorial Scholarship for 2014 will be available early in January.

**Visit Our Website at**  
[www.sbaneny.org](http://www.sbaneny.org)

**Like us on Facebook!**

## SBANENY FALL FAMILY WEEKEND RETREAT AT DOUBLE H RANCH SCHEDULED

**Dates & Times:** October 25<sup>th</sup> – 27<sup>th</sup>, 2013  
6 PM Friday evening through Sunday at noon

**Where:** Double H Ranch, Lake Luzerne, NY

**Who:** Children with Spina Bifida ages 5 to 21 and their parents/guardians & siblings

**What:** A weekend of activities designed to help families build and strengthen relationships with others faced with similar challenges.

**How:** As of this writing, 18 families are registered to participate in the weekend retreat. Additional applicants will be placed on a waiting list and called in the event that any of the registered families are unable to attend.

**Advanced Registration Is Required for the family retreat program.**

## SBANENY: HOW WOULD YOU LIKE TO GET INVOLVED?

Do you have skills in **Graphic Design**?

Do you have expertise with **Microsoft Access database software**?

**Party Planners!** Do you enjoy planning picnics, parties and events? We need a person (or more!) who can work with us to plan for the SBANENY Friends and Family Picnic in May 2014.

If your answer is yes to any of the above, please contact our office today. Your time and talents can make a difference today!

Of course, there are many other areas in which you may volunteer. Are you interested in getting involved? Let us know what your skills are!



## BOILERMAKER 15 K CHALLENGE 10-YEAR-OLD ACHIEVES HIS GOAL

Jason Robinson has been a fan of Utica's Boilermaker 15K Road Race for years. On July 16<sup>th</sup>, he accomplished a goal. In his first year competing in the race, he not only finished the race, but he exceeded his time goal. "I thought I was going to do an hour and thirty minutes, and I did an hour and thirteen minutes."



As Jason works toward his goals, he teaches awareness. He says that he wants other kids to know that just because they have a disability, it doesn't mean they can't do a sport.

Jason's goals don't stop with this past summer's accomplishments. "This is just the start.... I'm going to keep on doing it until I can't. I want to win the Boilermaker."

Jason was born with Spina Bifida and lives with his family in Central New York. To watch a video interview with Jason go to [http://www.cnycentral.com/news/story.aspx?id=924736#.Ulck8Xbd\\_IU](http://www.cnycentral.com/news/story.aspx?id=924736#.Ulck8Xbd_IU).

## SBANENY EQUIPMENT & SUPPLIES EXCHANGE PROGRAM

If you are interested in any of the items below, please contact the SBANENY office. We will provide contact information so that you may speak directly with the owners.

- ❖ Wheelchair Accessible Van being offered as a gift for a family or individual in need: 1996 Chevy Van, handicap accessible, Ricon power lift, hand controls on steering column, new retractable tie down straps, new transmission with transferable warranty. The van is offered in memory of Allison Mitchell.



- ❖ Electronic Recliner - from zero gravity to fully standing, for a petite person (great condition purchased from a medical supply store in 2011 used 1 year or less), solid blue

- ❖ Electronic Recliner - same as above but, additionally heat and massage components - a chair and one half size for larger size person (great condition purchased from lazy boy 2008 only used for 12 months) Both chairs are dry & covered.



- ❖ Scooter - an older model that worked perfectly. Comfortable seat & leg room for a person up to 5'8" NOTE: Ignition key is missing. Owner is reaching out to company for a replacement. New battery 2009 but has been sitting.



- ❖ Wheelchair: Size for a five year old child, 42", 35 pounds, who needs a light weight wheelchair.
- ❖ Wheelchair Accessible Van for Sale: 2003 Dodge Grand Caravan, IMS Rampvan side conversion and hand controls, 35201 miles and is in pristine condition.



The following items are available, first-come, first-serve, for anyone who might be in short supply on a temporary basis.

- ✓ catheters in a variety of styles and sizes
- ✓ Depends underwear for men, size S/M
- ✓ Lidocaine HCl Jelly 2%

Contact the SBANENY office about the items that you need and we will arrange for shipment.

Do you have new, sealed, unused catheters that are no longer of use to you that you would like to add to our supply at our office to be available for others? Contact our office.

Do you have equipment that you are no longer using and would like to pass along to someone who might benefit? Provide us with a description and, if possible, a picture and we will place it in this column.

## PROCLAMATION: ANNIVERSARY OF THE AMERICANS WITH DISABILITIES ACT

On July 25th, President Obama issued a Presidential Proclamation in commemoration of the 23rd anniversary of the Americans with Disabilities Act (July 26th, 2013).

"...Today, we celebrate the ADA's lasting

legacy as a pillar of civil rights. We also recognize that while the law continues to move America forward, our march to equality is not yet complete. Even now, barriers still keep too many people with disabilities from fully participating in our society and our workforce. Our country suffers when our citizens are denied the chance to strengthen our economy, support their families, and fully participate in our American life."

## AXIS DANCE COMPANY COMING TO GE THEATER AT PROCTORS

*The AXIS Dance Company creates, performs, and teaches physically integrated dance, a contemporary dance form that evolves from the collaboration between dancers with and without disabilities.*



**DATE:** Saturday, October 26<sup>th</sup>

**TIME:** 2 to 3 PM

**LOCATION:** GE Theatre at Proctors,  
432 State Street, Schenectady, NY

**FEE:** \$20 per person (*Proceeds support state-of-the-art equipment for the Neuro-Rehab Institute at Sunnyview Rehabilitation Hospital*)



Tickets are available through the Proctors Box Office, 518-346-6204 or [www.proctors.org](http://www.proctors.org). For more information, call Sunnyview Rehabilitation Hospital Foundation at 518-382-4586. For more information about the dance company go to <http://axisdance.org/#sthash.YfygzCOs.dpuf>

## **FRIENDS WHO CARE**

FRIENDS WHO CARE® is a disability awareness program -- it helps parents and educators teach kids about children and adults with disabilities.

FRIENDS WHO CARE is an interactive program designed to encourage kids to accept their peers with disabilities as people first, and to find ways to include everyone in school and after-school activities.

For more information, please visit: <http://www.easterseals.com/explore-resources/making-life-accessible/friends-who-care.html?autologin=true>

## **NEW YORK STATE JUSTICE CENTER VULNERABLE PERSONS CENTER HOTLINE**

The NYS Justice Center for the Protection of People with Special Needs has established the definitions of abuse and neglect of persons with special needs in broad terms, including both actual harm and the risk of harm. The Center maintains the Vulnerable Persons Central Register Hotline (VPCR). The VPCR is staffed 24 hours a day, seven days a week by 70 highly-trained call center representatives who were selected from a pool of more than one thousand applicants.

Reports to the VPCR Hotline come from many sources, including individuals with special needs who are receiving services, "mandated reporters" who comprise custodians, other health care professionals and law enforcement, as well as families and the general public. Anyone who witnesses or suspects the abuse or neglect of a person with special needs should make a report to the Justice Center VPCR Hotline by calling 1-855-373-2122.

To learn more about the NYS Justice Center, visit their website at <http://www.justicecenter.ny.gov/>.

## **SCUBA DIVING PROGRAM FOR INDIVIDUALS WITH SPECIAL NEEDS**

The Handicapped Scuba Association Training Center of New Jersey, with staff from CentraState's Star and Barry Tobias Health Awareness Center, OceanFirst Rehabilitation Center and the Fitness and Wellness Center are volunteering to provide free weekly scuba diving classes to children with special needs. The ongoing classes are held at the warm water pool at the Fitness & Wellness Center. Being in the warm water can help with muscle strengthening and breathing, improve motor skills, and build self-confidence.

Contact Ellen Stein, Program Coordinator at the Centra State Fitness & Wellness Center – 732-845-9400 or Stew Snyder for more information on Handicapped Scuba Diving – 732-928-0461

NOTE: Each class is for six Sundays. There is a waiting list.

## **ATTENTION HOMEOWNERS REGISTER FOR STAR EXEMPTION**

New legislation requires all homeowners receiving a Basic STAR exemption to register with the New York State Tax Department in order to receive the exemption in 2014 and subsequent years.

### **Who must register?**

Resident homeowners who currently receive the Basic STAR exemption must register with the New York State Tax Department in order to receive the exemption in 2014.

### **When Can I Register?**

Registration is through December 31, 2013.

### **How does a homeowner register?**

Online registration is available at [www.tax.ny.gov](http://www.tax.ny.gov).



# SBANENY DEVELOPMENT UPDATE

## SBANENY Direct Mail Campaign

In August, you should have received the SBANENY mail campaign letter. Over sixty families have already responded, making donations to support programs and services of SBANENY.

So far this year, the support of donors and sponsors has enabled staff and volunteers to provide;

- o Over 400 responses to individual needs of parents of children with Spina Bifida, adults with Spina Bifida, and service providers. Contacts have involved providing information and referral, support, information about Spina Bifida, and SBANENY programs.
- o Fourteen programs with a total of over 500 in attendance provided support, consumer networking and opportunities for social interaction, spina bifida and disability awareness, and community education.
- o Information and education totalling over 13,000 contacts reaching consumers, friends of SBANENY, and the general public, through mass mailing and emails.

*It is not too late to respond to the Direct Mail Campaign and join the sixty plus families who have already made donations!*

Donations can be made online through our website at [www.sbaneny.org](http://www.sbaneny.org). If you prefer, you can use the insert provided with this newsletter. Help Gabe hit the bullseye by making your donation today!

Thank you!

## SBANENY Walk-N-Roll

SBANENY Walk-N-Roll committee will begin monthly planning meetings soon. New people are always welcome! Would you like to help to plan for this important awareness and



fundraising event? Contact our office today!

## Dare to Dream with SBANENY...20 Years...

### Look How Far We Have Come!

Our Annual Fundraiser Committee is pleased to incorporate a 20<sup>th</sup> year celebration with this year's annual fundraiser. Over the last 20 years we have grown from providing support services for a few families in the immediate Capital District to reaching families throughout New York State. It is a good time to take a moment to celebrate and reflect. Please plan to join us on December 7<sup>th</sup> for this special event! The enclosed flyer gives some details. More will be available soon through our website and Facebook pages.

**For those who are unable to be there in person,** there will be an opportunity to participate in our unique silent auction. [Please watch for our online preview auction that will be open for pre-event bidding in mid-November.](#) This will be a great time to take care of some of your holiday shopping while supporting the SBANENY cause.

*Are you curious? How about.....*

- ✓ Southwest Airline tickets?
- ✓ Limo transportation from Albany to New York City with tickets to a comedy club?
- ✓ Gift certificate for a cooking class?
- ✓ Tickets to SPAC for the ballet?
- ✓ Autographed books?
- ✓ A bee house (Does that peek your curiosity?)
- ✓ And so much more! Check it out by shopping with SBANENY Silent Auction this Holiday Season!

**Sponsors!** We need sponsors for the Dare to Dream event. Are you interested in being a sponsor? Do you have a business contact who might benefit from the exposure while supporting the cause? Please contact our office as soon as possible and speak with Karen.

# ***Dare to Dream With***



**SPINA BIFIDA ASSOCIATION  
OF NORTHEASTERN NEW YORK**

**20 Years....Look How Far We Have Come!  
Fundraising Event!**

***Join us for***

***“The Singing Anchors” Holiday Show  
with Benita Zahn, Jessica Layton, & Jerry Gretzinger  
as originally produced at the  
Fort Salem Theater, Salem, NY***

***A night of music and more....***

**December 7<sup>th</sup> at 6:00 PM**

❖ **Appetizers & Desserts**

❖ **Silent Auction**

**SIVERhills Restaurant and Banquet House  
*at Pinehaven Country Club***

**Just a Tease or Two about our Silent Auction.....**

\* Perhaps a trip or two...

\* the perfect present for the one who has everything...

\* a gift for the nature lover...

**What's on your list?**

\* a book, fine food, some vino...

\* a night out on the town...

\* a vineyard tour...

\* a sparkling gem...

**Selected items from the silent auction will be available for pre-event bidding online. Check with our website, watch for emails, or like us on Facebook for updates!**

**Tickets will be available soon.**

[www.sbaneny.org](http://www.sbaneny.org)

[admin@sbaneny.org](mailto:admin@sbaneny.org)

518-399-9151





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# SBANENY CALENDAR OF EVENTS

WATCH FOR FLYERS,  
FACEBOOK UPDATES,  
EMAILS, AND OUR  
WEBSITE FOR  
INFORMATION ABOUT  
ADDITIONAL EVENTS  
AS PLANS ARE  
ANNOUNCED.

## OCTOBER

**October 25 – 27** Retreat Weekend  
for Families with Children with SB ages 5 to 21

## DECEMBER

**December 7  
2014 TBA** SBANENY Dare to Dream Fundraiser with SBANENY  
Adults – Developing Healthy Relationships  
Programs for Families with Children  
SBANENY sponsored regional conference  
SBANENY Walk-N-Roll for Spina Bifida 2014 TBA

**SBANENY BOARD MEETINGS** November 23, 2013, January 11, 2014

### *Estate Planning, Memorials & Honorariums*

*Have you considered including SBANENY in your estate plans? You may also want to consider honoring or memorializing a friend or a loved one with a gift to SBANENY.*

*For more information, contact Karen at 518-399-9151 or [admin@sbaneny.org](mailto:admin@sbaneny.org).*